

## **A Great Article on the Government's Failure to Address the CCSVI issue and a Typical, Uninformed and Highly Biased, Rightwing Response to the Article.**

Ashton Embry, January, 2011

On January 4<sup>th</sup>, two widely respected parliamentarians, Mr Ujjal Dosanjh and Dr Kirsty Duncan, published an excellent and insightful article on the government's obvious failure to properly address the issue of CCSVI and MS. Given that this abject failure is having a major negative impact on the health of tens of thousands of Canadians, this article was a very welcome and most important contribution to the current Liberation War in which persons with MS are battling neurologists, MS societies and governments to have proper research done on CCSVI and MS. Due to the substantial potential positive impact of CCSVI treatment for persons with MS and the consequent negative impact on the drug-revenue dependent neurologists and the MS societies they control, this war has gotten rather ugly and involved a lot of dirty tricks by the anti-CCSVI side.

In their article, Dosanjh and Duncan emphasized one of these nasty, dirty tricks - the unethical aspects of the government-requested committee on the need for CCSVI clinical research. The committee was jointly organized by the MS Society of Canada (MSSC) and the Canadian Institutes for Health Research (CIHR) and was stacked with people with a blatant financial conflict of interest and excluded anyone with any first hand knowledge or experience of the topic. Needless to say, this highly biased and ethically compromised, anti-CCSVI committee came up with a report which recommended that the government should not support CCSVI clinical research. I have already written a comprehensive analysis of the major scientific errors and ethical shortcomings of this committee and its report (<http://www.direct-ms.org/magazines/Analysis%20of%20Beaudet%20Report%2010%2009%2010.pdf>) and it was nice to see the authors bring these serious ethical breeches to the attention of the public.

Immediately after the publication of the Dosanjh and Duncan article, Chris Selley, wrote a negative blog on it in the National Post, a rightwing newspaper. It was entitled “Beware of politicians playing doctor”, a rather stupid title given one of the authors, Kristy Duncan, is a medical doctor.

My comments on the profound and somewhat venomous ignorance which characterizes Mr Selley’s blog are below. The article by Dosanjh and Duncan is in Appendix 1 and Mr Selley’s blog is in Appendix 2.

The lesson that can be learned from all this is that no matter how unethical and incompetent a government committee is, the rightwing bloggers will rise up to defend such unethical actions as well as the lack of credible science of the committee. They do not care about the negative impact that such unethical and inept actions have on the health of tens of thousands of Canadians. All they care about is glossing over the unacceptable and harmful actions of unethical committees such as the one put together by MSSC and CIHR in their continued and ugly efforts to prevent any meaningful research on CCSVI.

### **Comments on Chris Selley’s Blog “Beware of politicians playing doctor”**

Chris Selley, a blogger for the rightwing National Post newspaper, commented on the great article “Canada’s MS patients are owed an explanation” by Ujjal Dosanjh and Kirsty Duncan, two Liberal MPs who clearly care about the current plight of persons with MS in Canada. Dosanjh and Duncan focused on the unethical nature of CIHR/MSSC Committee which looked at the need for clinical research into the efficacy of CCSVI treatment for MS. The authors correctly pointed out that those with expertise in the subject matter at hand were purposefully left off the committee for the absurd reason that such expertise would bias the committee’s decisions. The authors also importantly pointed out that many of the committee members had a serious financial conflict of interest when it came to making a decision on a potentially very beneficial, non-drug treatment for MS.

For some reason I cannot fathom, Mr Selley seems to think such criticisms of the membership of a committee, charged with a very important decision which will affect the health of tens of thousands of Canadians, are not just. I can only assume that Mr Selley thinks committees charged with making important decisions should exclude any person with experience and relevant expertise in the subject at hand and be stacked with individuals with a major conflict of interest.

I am sure Mr Selley would approve of a committee charged with looking at the tax structure applied to the petroleum industry being filled with persons who receive significant compensation from the petroleum industry and being void of any individual with experience in developing a tax structure for the petroleum industry.

There are certainly a number of other errors and misconceptions in Selley's less than stellar blog on the excellent Dosanjh and Duncan article. There is no doubt I could write four or five pages on all the inaccuracies and bad logic that litter his blog but why bother. You stamp out 10 cockroaches and 50 more soon appear. Pointing out the shortcomings of blogs and articles by uninformed, and in the case of Mr Selley, sensationalistic, writers is potentially a never-ending task when it comes to the science of CCSVI.

Mr Selley and his journalistic colleagues have little to no knowledge or experience in the world of science and, not surprisingly, are constantly creating a nonsensical mishmash of facts, myths and misunderstandings in their earnest but failed attempts to produce intelligent comments on scientific matters such as CCSVI and MS.

Take for example his quote from the Alberta Health Services Information Sheet on CCSVI and MS, a document which is replete with numerous factual errors, misleading statements, half truths and blatant, fear mongering all documented at <http://www.direct-ms.org/magazines/An%20Open%20Letter%20to%20the%20Honourable%20Gene%20Zwozdesky.pdf>. Selley impressively uses one of the dumbest statements from that report which is characterized from start to finish with moronic lines – ““We know that people with MS have a 75% chance of being female while those without MS only have a 50% chance of being female. However, being female is not the cause of

MS.” The authors of the report and Selley were trying to get across, with an inappropriate and silly example, the basic concept that association does not equal cause which I think needs no explanation to any human being capable of reading.

Of course, the authors of the AHS report and Mr Selley did not mention that strong association of the factor and the disease, plus appearance of the factor before disease onset, plus reasonable biological mechanisms tying the factor to the disease process, together all provide a reasonable suspicion of a causal relationship that needs further investigation. Needless to say CCSVI fulfils all these criteria when it comes to MS and that is why it is likely part of the MS disease process and why a proper clinical trial is needed as soon as possible.

Now should we expect Mr Selley to understand all of this. Of course not. However, because he has no understanding of science, he really should stick to non-scientific topics (like his enjoyable and harmless blog on why he doesn't believe in god

<http://fullcomment.nationalpost.com/2010/12/23/chris-selley-the-happy-heathens/>) and save himself a lot of embarrassment.

Furthermore, given Mr Selley's impressive display of a complete lack of common sense, his inability to comprehend scientific principles, and his poor understanding of what constitutes unethical behavior, it is clear that **people have to Beware of Rightwing Bloggers Playing Journalist.**

## **Appendix 1 - Canada's MS patients are owed an explanation**

Ujjal Dosanjh and Kirsty Duncan, January 04, 2011

The government of Canada is failing multiple sclerosis patients on numerous fronts.

In August, the Canadian Institutes of Health Research, in collaboration with the Multiple Sclerosis Society of Canada (MSSC), convened a "meeting of top researchers ... with a special emphasis

on neurovascular issues including the recently proposed condition called CCSVI."

Sadly, it was an expert group with no experts in the imaging/treatment of chronic, cerebrospinal venous insufficiency (CCSVI).

Leaders, such as Dr. Sandy McDonald -- the only Canadian to be trained by liberation treatment pioneer Dr. Paolo Zamboni, and to have performed the procedure here in Canada -- were not consulted.

Moreover, there was no inclusion of international experts in CCSVI/liberation treatment, no data presented at international scientific conferences, and no site visits to labs and operating theatres, but rather just blind acceptance of a handful of studies, including two which had been accepted in an astounding six weeks.

After the secret meeting, we were told, incredibly, that CCSVI/liberation experts were not included for fear of biasing the discussion; surely, disregarding experts is a dangerous precedent. Yet researchers, who had vehemently spoken out against the liberation procedure, were included in the group.

A new "scientific expert working group" has been appointed, but sadly suffers the same flaws as the initial group -- namely, no experts, no experience, and many undeclared conflicts of interests. The new group is to ana-lyse interim and final results from seven Canadian and U.S. MS Societies -- funded studies, for which we already have answers.

Why is the government waiting for results when more than 3,500 procedures have been performed in more than 50 countries; when Bulgaria, Canada, Italy, Kuwait, Poland, and the United States report that 87 to 90 per cent of MS patients show one or more venous abnormalities in MRIs and ultrasounds, and 97 per cent when angiography is done?

Canadian MS patients deserve evidence-based medical practices. But how can this right be realized when their government refuses to

collect any evidence? We have been calling for the collection of evidence since the spring, through clinical trials, and a registry.

It is more than unfortunate that Canadian patients, who have been travelling overseas since January 2010, have not had their results tracked, for example, at one month, three months, and six months after treatment. One Canadian neurologist, who had the liberation procedure, said to me, "if we had collected the evidence in a registry for the last many months, would we still be calling these anecdotal stories?"

Finally, like many MS patients, we are frustrated with the government, and want an investigation into how this file was handled so badly: how special interests co-opted science; how an organization that was supposed to steadfastly advocate for MS patients flip-flopped on its position; how process was used not to do science; how conflicts of interests went undeclared; how a pioneering surgeon had to risk his reputation; how MS patients were forced to fight the system; and how the minister repeatedly failed to advocate on behalf of suffering Canadians, particularly with regard to followup care -- especially when we began raising the issue in July with officials?

And ultimately, who was responsible for repeatedly failing to take leadership, and who must be held accountable for the abject abdication of responsibility?

## **Appendix 2 - Beware of politicians playing doctor**

Chris Selley January 4, 2011

Mainstream medical opinion is roundly skeptical of Paolo Zamboni's "liberation" treatment for multiple sclerosis, but that's not to say the Italian surgeon won't one day be vindicated. As many have pointed out, nobody believed the *Helicobacter pylori* bacteria caused stomach ulcers either — but it does. It's possible cerebrospinal venous insufficiency (CCSVI) — the name Dr. Zamboni gave to ostensibly constricted neck veins, which he relieves with angioplasty, often to rave reviews — will eventually be acknowledged as a key piece of the MS puzzle.

If so, Canadian politicians will be able to take some credit. Alberta, Newfoundland and the federal government have all agreed to spend money studying the treatment, and Saskatchewan plans full clinical trials. If they were honest, though, some of those politicians would admit they weren't entirely motivated by an unquenchable thirst for medical truth.

Liberal leader Michael Ignatieff, who promises to fund clinical trials as prime minister, would be one. "Why can't Canadians get a shot at getting at something that might have a therapeutic benefit?" the erstwhile professor asked last month, seemingly opening the door to everything from leech therapy to trepanation. Based on their op-ed in Tuesday's Ottawa Citizen, Liberal health critic Ujjal Dosanjh and MP Kirsty Duncan would be two more. I claim no significant expertise on MS or CCSVI, but I know bad arguments when I see them.

Here's one: Mr. Dosanjh and Ms. Duncan claim that the "scientific expert working group" on CCSVI, assembled by the Canadian Institutes of Health Research, includes "no experts, no experience, and many undeclared conflicts of interest."

Pardon? That's 23 individuals they're impugning there. They include respected neurologists from the Ottawa Hospital, the Cleveland Clinic, St. Michael's Hospital in Toronto, NYU and the Universities of Calgary, Wisconsin, Saskatchewan, British Columbia and Texas. So, what are these conflicts of interest? CCSVI activists such as Ashton Embry, a Calgary geologist, insinuate some working group members are in the pocket of pharmaceutical companies, which profit from current approaches to MS treatment. But that would be pretty strong stuff for politicians to hurl at respected physicians — so they don't. They just drop the stink bomb and flee the scene.

Moving on, Mr. Dosanjh and Ms. Duncan claim not to understand why the government is dragging its heels on clinical trials when "87% to 90% of MS patients show one or more venous abnormalities in MRIs and ultrasounds, and 97% when angioplasty is done." You'll find such numbers on websites trying to sell liberation therapy tourism, but if you consult more disinterested sources you'll see that findings differ markedly. A randomized University at Buffalo study released in February, for example, found that only 56.4% of MS sufferers had CCSVI (and 22.4% of non-MS sufferers had it too).

Regardless of the numbers, as Alberta Health Services noted in a level-headed August communiqué, there's the small matter of correlation vs. causation to consider: "We know that people with MS have a 75% chance of being female while those without MS only have a 50% chance of being female. However, being female is not the cause of MS." One can just picture a politician's eyes glazing over.

The Liberals like to portray themselves as the party of science and reason and the Conservatives as the party of mulish right-wing stupidity. On the mandatory long-form census, on crime prevention, on climate change, on the importance of abortion for maternal health in the developing world, they are comfortably in and of the mainstream.

"The government is slaughtering good medical practice on the altar of ideology," MP Dr. Keith Martin complained when the Tories insisted family planning had nothing to do with maternal health — and he was right. On the MS file, however, the Liberals are way out in left field. And we all know why: Because there's nothing in it, politically, for them not to be.

It took some flaming cheek for Mr. Dosanjh and Ms. Duncan to claim that "disregarding experts is a dangerous precedent" in an op-ed that involved disregarding — not to mention disrespecting — literally dozens of medical practitioners and researchers. But precious few politicians are capable of resisting the lure of emotionally charged issues, and the opportunities they afford to care out loud. From this appalling cynicism, there seems very little hope of liberation.